INSTITUTE OF PUBLIC HEALTH

COLLEGE OF MEDICINE AND HEALTH SCIENCES

UNIVERSITY OF GONDAR

DISCLOSURE OF THEIR HIV STATUS TO HIV INFECTED CHILDREN BY CAREGIVRSOR PARENTES AND ASSOCIATED FACTORS IN DESSIE REFERRAL HOSPITAL, NORTHEASTETHIOPIA.

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Acronyms

3TC…… Lamivudine

ABC……Abacavir

AIDS…… …… ….Acquiredimmuno-Deficiency Syndrome

ART…….....Anti-Retroviral Therapy

ARV…….Anti-Retroviral Drug

AZT/ZDV ……....Zidovudine

CD4 CELLS ……...Type of T-lymphocyte, white blood cells

CD4……..Cluster of Differentiation

EFV ……Efavirenz

EMOH …… …….Ethiopian Ministry of Health

EMTCT……..Elimination of Mother to Child Transmission of HIV

ETB……Ethiopian Birr

HAAPCO…… HIV/AIDS Prevention and Control Office

HAART…… Highly Active Anti-Retroviral therapy

HIV……Human Immunodeficiency Virus

IDV……Indinavir

OI……Opportunistic Infection

OR…….Odds Ratio

RHB……...Regional Health Bureau

SD…….Standard Deviation

WHO……..Wereda Health Office

WHO…….World Health Organization

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Abstract

Introduction: Disclosure of children HIV status to HIV infected children by caregivers or parentsare being important medication adherence, prognosis of illness, improving restoration of Immunity and Psych-social well-being of coping skills. Disclosure is a process and not an event that takes time and constant communication in an age-appropriate manner Human Immunodeficiency Virus- infected children live longer with the introduction of antiretroviral drugs.

Objective: The aim of the study was to assess disclosure of children HIV status to HIV infected children by caregivers or parents and associated factors inDessie Referral Hospital North East, Ethiopia.

Methods: Institutional based cross-sectional study was conducted among 290 HIV infected Children caregivers or parents at Dessie Referral Hospital from March to May 2015; systematic random sampling technique was used to select HIV-infected children ages 5–14 years attending at ART clinic. Data were collected from questionnaires administered by clinicians to their caregivers, supplemented with chart review. Descriptive statistics and disclosure prevalence were calculated. Bivariate and multivariate logistic regression was performed to assess the association between disclosure and the independent variables AOR with 95% CI was computed..

Results: Prevalence of disclosure was 32.1 %(95%CI: 27% - 38%), mean age of the children was 10.44 (± 2.7) years, the mean age of Disclosure was 10.1(±1.9)years and 53.1% were Male. In multivariate regression, younger age (OR=0.025, 95%CI:0.005 –0.119), children Not started education (OR= 0.182, 95%CI: 0.42– 0.798) , Non-biological caregivers (OR=4.04,(95%CI:1.573 , 10.374) , caregiver-reported Adherent (OR 6.939, 95%CI 3.122 – 15.422) and < 350 cell/mm3 /CD4(OR = 3.221:95%CI:1.406 – 7.175) were with HIV disclosure status.

Conclusions and recommendation: The Prevalence of HIV status disclosure among children were found to be low which has been associated with their Age of child, Educational status of childs,CD4 count, Non-biological parents and Adherence. There should be regular and conceptual way of disclosure to children.

Keywords: HIV; disclosure; children; North East Amhara, Ethiopia

1. Introduction

1.1 Statement of the Problem

In 2014 UNAIDS report 3.4 million children under the age of 15 years living with HIV worldwide , almost 90% live in sub-Saharan Africa(1), After the advent of the HIV epidemics, initially due the short survival time of prenatal infected infants and children, disclosure of their HIV positive status was not given close attention(2). Later, experience from other chronic illnesses, especially cancer was considered in stating that disclosure to children is beneficial to their self-esteem and will help them to participate in their own medical treatment. Applying the evidence-based knowledge being practiced within oncology to pediatric HIV disease is difficult given significant differences in epidemiology, the multigenerational nature of the illness, and the unique social stigma surrounding HIV transmission(3).

Disclosure is the act of disclosing, uncovering or revealing; bringing to light; exposure(4).Disclosure is a process and not an event that takes time and constant communication in an age-appropriate manner(5). One of the biggest psychological challenges that healthcare provider and parents face is disclosure of status perinatal infected HIV positive children, disclosure has potential to affect a child psychological well-being in addition to his/her physical health in the context of chronic illness(6).

Despite it is difficult to generalize many caregivers are reluctant for children living with HIV to let them to know their status, arguing that they are too young, may not understand fully what is happening, may encounter emotional disturbances as a result, may blame their parents and ask questions on how they got the disease, and may inadvertently speak out the secret, exposing the family to stigma and discrimination(7, 8),Therefore, questions such as when to disclose, who should disclose, how and how much to tell, have been controversial for some time. while the latter stand by the child's right to know and participate in decision-making about treatment in an age-appropriate manner(9).

The prevalence of disclosing of HIV status to infected children has been found to be low in different low and middle income countries (10-12).

The pediatrics HIV population in Ethiopia , mostly older children who were vertically infected in earlier years when the coverage and effectiveness of PMTCT in the country was low/MTCT rates high (in 2013 163,800 HIV positive children were aged 5-14 years)(13). In Ethiopia studies have done in Addis Ababa, Bahirdar and Gondar the prevalence of Disclosure is(17.4, 35.1 and 39.5 percent) respectively for all the reason on non-disclosing is similar but other factors associated with adherence ,improving disease prognosis and psychological outcomes did not included in their study of pediatrics patients to Antiretroviral therapy (ART)(12, 14, 15).

The disclosure of HIV status to children is not yet studied in this health care facility and it is not known whether it may influence their clinical response to ART.

1.2 Literature Review

1.2.1 Magnitude

A different studies concerned that parents/caregivers are afraid that they will be at risk of depriving the child of a happy childhood(16), and will overburden the child with worries that are beyond its age. The reason the child is too young is given by caregivers in different studies in Brazil(17). AStudy conducted in Thailand28.1% showed that parents/caregivers felt that their child was too young(18), while the same was true for 57.1 percent in a study in Ethiopia(14). Though it is true that children may be too young to understand their disease, this needs to be discussed and validated with caregivers so that age-appropriate disclosure can be conducted, based on the child's level of illness understanding(19).

Guilt: Parents/caregivers may not want to discuss because they do not have enough time to process the diagnosis themselves. They may still be in denial. They may also need to disclose a family secret about how the disease was acquired(9). Biological parents may be specially challenged if disclosing the child's status means they automatically disclose their own (19), and so may also feel guilty for having transmitted the HIV virus to the child. This may result in questions from the child that they are not ready to answer. Studies cite cases of fear in parents that the child might ask how they got the disease, be angry at them for giving him HIV and act out these feelings.

Fear of emotional distress However, beyond the direct effects on children's neuron-cognitive and psychological functioning, HIV infection may disrupt many of the social support systems that children depend on for optimal development(19).Study conducted in Ethiopia the barriers to disclosure is the fear of causing children emotional or psychological problems. Parents fear that the children will experience depression upon hearing their diagnosis and may lose their will to live nearly 43% of caregivers in one study stated that they fear that disclosure might have negative psychological consequences to the child(15).

Stigma : study conducted identify stigma as being one of the main reasons parents delay disclosure, state that Caregivers identified barriers to disclosure including fear

of discrimination, fear of social rejection and isolation(19). Caregivers fear that the disclosure to the child will lead to inadvertent disclosure by him or her to others, so that the secret of the family will be known, leading to discrimination against the child and the whole family. A study carried out in South Africa showed that 73% of caregivers fear the child will disclose to others, and that is especially sensitive in large families with both HIV positive and negative members. The study states that as HIV infection remains highly stigmatized in south Africa communities, disclosure of pediatrics HIV infection may also be accompanied by threats to the child's physical and/or psychological health(20).

Lack of knowledge: Study conducted in Thailand many of caregiver's beliefs that the child has to be told; they felt helpless since they did not know how to do this in the least painful way possible. Therefore, they tended to postpone this as long as possible. Some even hope that the child would be able to find out about their status on their own (19).

1.2.2 Factors Associated With Disclosure

Child's right to know: Studies conducted in America showed that Parents expressed concerns about the language of rights, which they perceived as giving too much liberty on children, but despite that parents also believed that children, depending on their age, had a right to know that the virus affected them(21) ,Another studies conducted in Europe, disclosure for children under six was found to be mostly influenced by parents perception of child needs, including the right to know, but the rights are not limited to knowledge of the disease, but also involve the right to participate in decisions with regards to their treatment(22). In another study in South Africa, that 98% of biological parents in research stated that concern for the right of the child to know his diagnosis was their main reason for full disclosure(20) .

Better participation regarding treatment and adherence:Disclosure of HIV status to HIV infected children has associated with medication adherence, A study in Belgium concerning children 0-18 years found that some care givers reported higher adherence when children were aware of their HIV status(23), and also parents of children who refuse to take medicine or go to the clinic may wish to use disclosure as a means of creating better involvement by the child to all treatment, but more

specifically for improved adherence to ART(21).There are also instances when disclosure happens accidentally by parents who come up with the truth in a burst of anger at their child's unwillingness to take the drugs. Studies conducted in losangeles USA that disclosure of HIV status has resulted in better adherence ,while that the majority (58%) of children who knew their HIV status adhered well to their HAART regimen After a qualitative study conducted In addition to the poor palatability of medication and/or high pill load, two major barriers to adherence are children's lack of awareness of his/her HIV status and the monotony of the never-ending treatment process(24).Other possibilities mentioned are negative reactions to disclosure leading to non-adherence and abstaining from taking medication due to fear of one's status being discovered by others(25). and also in Uganda study has conducted with 42 participants who were caregivers of HIV positive children aged 5-17 (median years) among those result showed that when children where non-disclosed caregivers to child HIV status the child was three times less likely to Adhere to Highly Active Antiretroviral Therapy(26) . further studied that if these factors were controlled, there was no significant association between adherence and disclosure (6), One other possibility is that after disclosure parents assume that children will take full responsibility for their medication, as in one study which found that prematurely releasing responsibility for ART to children results in poor adherence(27)Despite the general assumption that disclosure improves adherence by creating a better understanding by children of the need to take ART and enhancing trust, In Addis Ababa multicenter institutional studies conducted that children who knew their status are less adherent or non-adherent(12).

The difficulty in comparing these studies with those that claim better adherence with disclosure is due to such factors as different methodologies, sample and age groups. As a significant number of studies with adherence use self-report to assess adherence, recall bias can also be a challenge. Many being cross sectional, the question arises as to how it is possible to assess the time factor, and whether non-adherence precedes disclosure or if disclosure has resulted in non-adherence.

The following studies seem to support this argument. The first, a qualitative study found that disclosure was taken as a necessary step to enhance adherence, because children could not understand why they needed medicine while they were

healthy. However, an interesting finding in this study was that adherent caregivers who disclosed to children agreed that children were more adherent, but less adherent caregivers reported that non-adherent children became even more difficult after disclosure(23).

A three year retrospective study on a cohort of 325 HIV-infected Romanian children receiving highly active antiretroviral therapy, finding significant associations between not knowing the HIV diagnosis and death, and not knowing the HIV diagnosis and disease progression defined as either death or CD4 decline that in the era of highly active antiretroviral therapy knowledge of one's own HIV infection status is associated with delayed HIV disease progression(28)This would need further research as it would increase the importance of disclosing their HIV status to children.

Psychological benefits: Evidence on the emotional and psychological impact of disclosure was more limited. In the only study identified that quantified the psychological differences between disclosed and non-disclosed children, children in Zambia found non-disclosed children were more than twice as likely to experience concerning levels of emotional difficult . In qualitative studies, many youth reported initial emotional difficulties, some of which were mitigated over time. In a qualitative study of 25 South African adolescents, almost all found disclosure to be emotionally difficult(29). In Brazil and the DRC, children reported feeling sadness, grief, and worry upon learning about their HIV infection, but these negative feelings were followed by some feelings of relief(17). Congolese children reported feeling calmer after disclosure because knowing their HIV status removed some of the uncertainty surrounding their illness(30). Despite the negative emotions of sadness and worry, A study reported that children felt that knowing HIV status was important and necessary(31).

Avoidance of accidental disclosure: One factor that emphasizes the importance of disclosing at the appropriate time is the risk of accidental disclosure to the child which can happen either at home or in clinical settings. There are reports in the literature about parents who are tempted to disclose to their child in anger, for example when the child refuses to take medication. This is a less than ideal situation

and can be traumatic for the child who may associate the experience of disclosure with guilty feeling. Another possibility is for children to find out their status inadvertently in clinical settings(32, 33). The case of an eight year old child finding his diagnosis accidentally in a clinic resulted in the child's screaming and being very disturbed by the news. The problem was compounded by a mother who was not ready and denied to the child that he was HIV positive(27).

Disclosure of their status to children helps to maintain their right to know and participate in their care, maintains their trust in their family, healthcare providers and community, and may improve adherence, improve progression of illness, improve CD4, lowering symptom of depression and stigmatization. It also provides them with access to support. Conversely, non-disclosure seems to have a more profoundly negative effect on children's disease progression, decline of CD4, poor adherence, emotional and mental status. All these factors show the importance of disclosure as part of HIV/AIDS care and support that need for it to be addressed routinely(32, 33).

Conceptual frame work

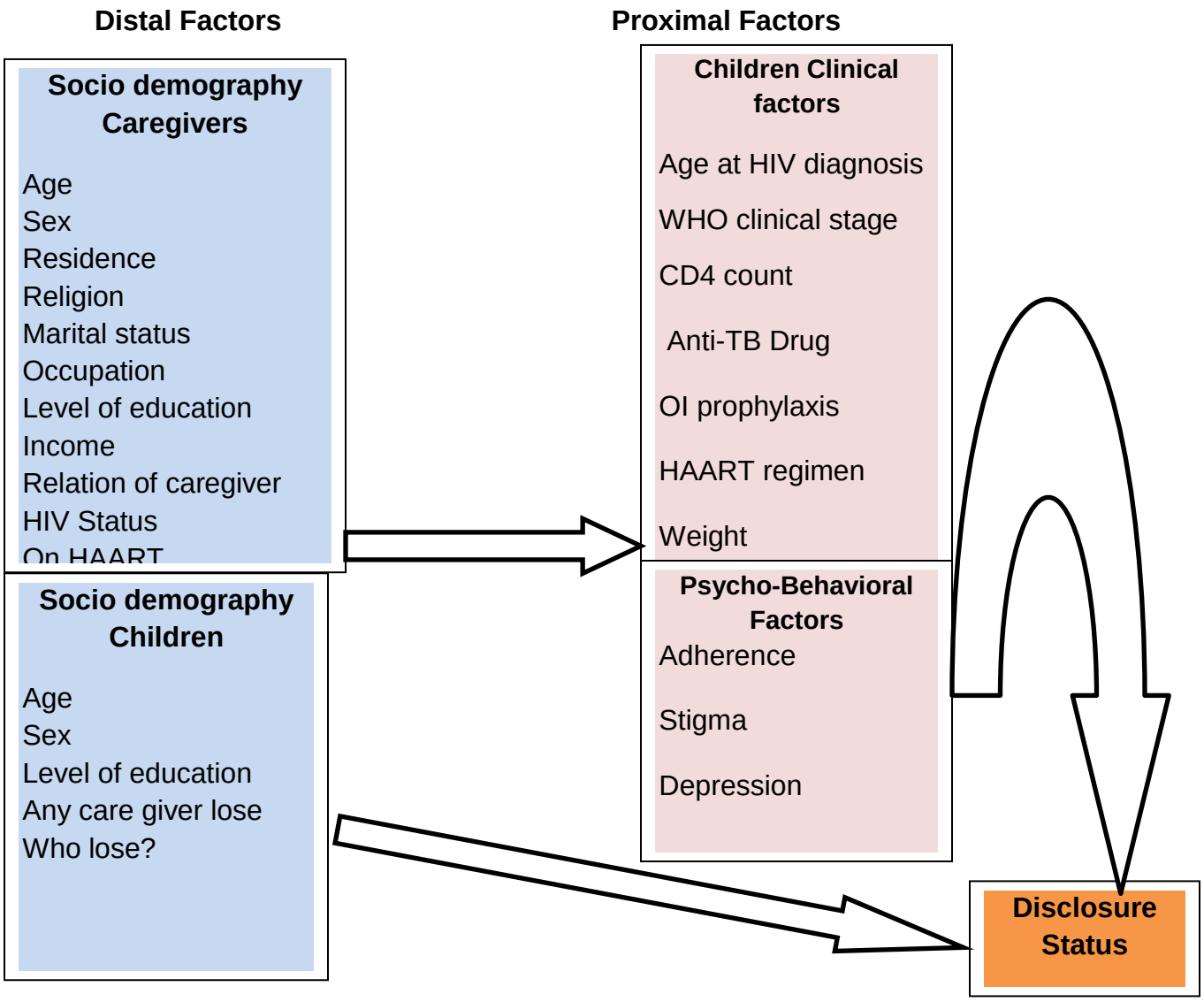

Figure 1: Conceptual frame work for Disclosure of HIV status to HIV infected children in Dessie Referral Hospital May 2015.

1.3Significance of the study

According to 2014 Ethiopian MOH new ART guideline which is recommended for HIV infected all children less than 15 years regardless of CD4 count and WHO clinical stage therefore disclosure of the HIV positive status to HIV infected children have benefits of psychological (facilitate children's adjustment), and positive effects on the clinical course of the disease, increase adherence to mediationsand Improve diseases progression.

Therefore the magnitude of disclosure did not studied in this heath facility setting and this studywas used to determine the current magnitude of disclosure in study setting andalso Associated factors including variables such as clinical indicators , medication adherence, stigma and depression which have not been including previous studies.

2 .Objectives

2.1 General Objectives

To assess disclosure of HIV status to HIV infected children and associated factors in Dessie Referral Hospital, North-East Ethiopia.

2.2 Specific Objectives

To estimate magnitude of Disclosure of HIV status to HIV infected children receiving care in DessieReferral Hospital.

To identify factors associated with Disclosure ofHIV-status disclosure to HIV-infected children receiving care in Dessie Referral Hospital.

3. Methods and Materials

3.1 Study Design

Institution based cross-sectional study was conducted.

3.2 Study Area and Periods

The study was conducted at Dessie referral Hospital HIV care clinic from March 26 to May 13, 2014. This hospital is found in Dessie town located in South wollo administrative zone, Amharic National Regional state, which is found at about 400km Northeast of Addis Ababa (the capital city of Ethiopia) and 485km from Bahirdar (Amhara regional capital town) According to the 2007 population and housing census report, the total population size of Dessie town was estimated to be 81, 042. This town is experiencing fast growth and according to the Dessie town Health office report currently Dessie town has two Public Hospital, three private general hospital, eight government Health Centers, five specialty clinic and more than seven Medium private clinics. Dessie hospital was established as a general hospital since 1962 dedicated to provide medical, surgical, obstetrics and gynecology, pediatrics and emergency service currently the hospital has a total of 420 paid staff (291 technical and 129 administrative staff).Ithas 200 beds and it serves about eight million people coming from neighboring zone and region.

The HIV care service of the Hospitals was initiated in 2005 and has three clinics: Adult ART clinic, Pediatric ART clinic, and VCT clinic. The clinic has one medical doctors providing ART services, 2 BSc. and 3 Diploma nurses, 2 data clerks, ,1 porter, 1 janitors, 2 case manager and 5 adherence supporters (people living with HIV). The Hospital uses standardized monitoring and evaluation tools and the data collection and management process is well controlled and supported by electronic data back-up and processing. Adults and Pediatrics were about 5102 and 734 who are taking currently on ART respectively.

3.3 Source and Study Population

The source population was all children living with HIVwho ever registered to chronic HIV care and support program in South wollo.

The study population was those children living with HIV who were enrolled to chronic HIV care and currently on follow up at Dessie Referral Hospital.

3.4 Inclusion and Exclusion Criteria

Inclusions: children age between 5 -14 years old who were enrolled in chronic HIV care at pediatrics ART clinic ofDessie Referral Hospital was included.

Exclusions: children who came by themselves or without caregivers.

3.5 Sample Size and Sampling Techniques

The sample size of the study was calculated by usingEpi info 7 stat calculation of single population proportion (34)

N= $\frac{z^2_{\alpha/2} \times p(1-P)}{w^2}$ Where; n= sample size:

Observed Prevalence=39.5 proportion of HIV status Disclosure to their children (14)

Assumptions:

Confidence limit = (margin of error) = 0.04

Z = value of standard normal distribution at 95% confidence level (z=1.96).

n = 284 subjects

10%non-response rate, 284 + 284 X 0.1

N= 312subjects

systematic Sampling technique was used by selecting one of the days of the week randomly to start andfirst were selected by follow up date from computerized database then Selected the first children from first day list one to two by lotterymethod and then was taken every other childrenuntil the desired sample size of 312 was reached (interval size, K = N/n = 562/312 =2)

3.6Variables of the Study

Dependent variable: children HIV/AIDS disclosure status (Yes/No),

Independent Variables:

- Socio-demographic Characteristics

  Childs: Age, Sex, level of education,

  Care givers: Age sex, level of Education, income, residence, occupational status, marital status, religion.
- caregivers level factors

  Relationship with the child (Parents or non-Parents)

  HIV and Treatment status

  Reason for disclosing and not disclosing

  Perceived advantage or disadvantage of disclosure

  Future plan to disclosure

  Preference by whom the child todisclosed, Family status (Alive/dead father, mother, or other family member)
- Child health related status from child secondary data

  Age at the time of diagnosis

  Treatment status (on HAART, Anti-Tuberculosis andCo-trimoxazol)

  WHO Clinical stage (current)

  CD4 Count (current)

  Adherence status documented

  Weight (current)
- Factors Adherence, Stigma and depression caregivers question from Questioner Disclosure.

3.7 Operational definitions

- HIV Diagnosis disclosure: Disclose if the caregiver were answered yes at least one of the questions and non-disclose if the caregivers were answered NO for all four questions from Questionnaire (308 - 311).
- Adherence: Adhereif the care givers were answered No forall four questions or Non-Adhere If the caregiver's wereansweredyes at least one of the question From Questionnaire (401 – 404).
- Stigma: Stigmatize if the caregivers were answered yes at least one question or non- stigmatize if the care givers were answered No for all three question from questionnaire (405 – 407).
- Depression: Depressed if the care givers were answered yes at least one question or Non Depressed if the caregivers were answered No for all two question from questionnaire(408 – 409).PHQ-2 a tool which is used easily diagnose Depression at primary care setting and it took from patient health questionnaire-9(PHQ-9)(35).

3.8 Data collection tools and Data quality control

Data wascollected by using structured questionnaire. The questionnaire wastranslated Amharic to prepared then re-translated back to English to make reliability of the instrument, Before undertaking the data collection the instrument was tested taking 5% eligible for feasibility of the questionnaires and One supervisor and three data collectors were participated in the data collection process. One day intensive training was given to the data collectors and the supervisor on how to conduct the data collection, data were gathered mainly through patient interview and revising medical records.

3.9Data processing and analysis

After the data were checked for its consistency and completeness, it was entered to EPI- INFO version 7 then exported to SPSS version 20 for analysis. Data were entered by the principal investigator and cleaned before analysis. Data result was presented through tables and graphs. Both bivariate and multivariate logistic regression model were used to identify significant variables, those Variables with p value<0.2 in the bivariate analysis were entered into the multivariate logistic regression. Ninety five percent confidence interval of odds ratio was computed and variable having p-value<0.05 in the multivariate logistic regression model was considered as significantly and independently associated with the dependent variable.

4. Ethical Considerations

Ethical clearance was obtained from Institution review board of the Institute of Public Health, Collage of Medicine and Health Science, University of Gondar. Permission for conducting the study was secured from the Amhara regional health bureau and Dessie referral hospital Administration. Then written Consent/ finger print were obtained from all the study participants (only parents/caregivers) after they briefly informed about the objectives and the aim of the research. Confidentiality were maintained at all levels of the study by not writing the respondent's name on the questionnaire and the information weregot from the respondent not be shared for other persons and. Participant's had full write t involvement in the study were on voluntary basis; participants who are unwilling to respond to the questionnaire and those who wish to quit their participation at any stage were informed to do so without any restriction. All sample populations were encouraged to participate in the study.

5. Dissemination of Results

The result was summated as partial fulfillment of the degree of Master of Public Health in epidemiology and biostatistics to the institute of Public Health, College of Medicine and Health Sciences, University of Gondar.

It will be also disseminated to Dessie Referral Hospital, Amhara regional Health bureau, South wollo Health Department and other governmental and none governmental organizations who are specially working on HIV/AIDS . The result will be also presented at University of Gondar annual research conference, and other conferences and workshops. Moreover, the result will be sent for publication at scientific National or international journals.

6.Results

6.1Socio-Demography characteristics of the study caregivers/Parents

A total of290 care givers of children respondents were included in the study with response rate of 93% of children age (5-14) years old on HAARTprovided information on the children under their care. The mean age of caregivers was 37.8±10.6 and almost more thanhalf 56.6% of them were in the age group 30- 50 years old.

Above three-quarters of 87.2% caregivers were living in urban, About 79 (27%) of caregivers were attending primary education and 151(52.1%) the caregivers were married ,Half of 51.4 % had less than 500 birr monthly income and 83(28.6%) were housewife , more than 46.9% were Muslim followers. In addition, data were collected on the caregivers' sex about210(72.4 %) of the caregivers were Female.Approximately, three fourth 72.1%of caregivers were HIV positive, out of these 94.7% have been put on highly active antiretroviral therapy. Lastly, the majority caregivers 223(76.9 %) were biological parents (Table1).

Table 1: Socio-Demographic characteristics of Caretakers/parents in Dessie Referral Hospital, 2015

Variables	Frequency	percentage
Residence		
urban	253	**87.2**
rural	37	12.8
Age of Caregivers		
< 30 years	89	30.7
30-50 years	164	**56.5**
>50 years	37	12.8
Sex of Caregivers		
Male	80	27.6
Female	210	**72.4**
Educational status caregivers		
No formal education	75	25.9
Primary(1-8)	79	**27.2**
Secondary(9-12)	77	26.6
College and above	59	20.3
Marital status		
married	151	**52.1**
Single	42	14.5
Divorced	39	13.4
windowed	58	20.0
Religion		
Orthodox	98	33.8
Muslim	138	46.9
Others	56	19.3

Occupational status		
Housewife	83	**28.6**
Government	49	16.9
Farmer	31	10.7
Merchant	46	15.9
Daily laborer	60	20.7
others	21	7.2
Monthly income		
<500 birr	149	**51.4**
500 -1000 birr	61	21.0
1000 – 2000 birr	30	10.3
> 2000 birr	50	17.3
HIV status of Caregiver		
Positive209**72.1**		
Negative	8127.9	
ON HAART		
Yes	198	**94.7**
No	11	5.3
Relationship with children		
Biological parents	223	**76.9**
Grandparents	33	11.4
Relatives	34	11.7

6.2 Socio - Demographic characteristics Children's

Of 290 children age 5 - 14 years old, more than half of 154(53.1%) were male. The mean age of the children was (10.44 years ±2.7). More than half, 65.9% children were between the ages (10 - 14 years old), while the rest 34.1% were between (5 - 9 years old). The majority of the children 225(77.6%) were attending primary school. More than one third of the children were orphans (41%) with orphan defined as having a deceased biological mother, having a deceased biological father or having both. Most of 76.6 % were Biological caregiver of the children (Table 2).

Table 2: Socio-Demographic characteristics of children Age of 5 to 14 years old, in Dessie Referral Hospital ,2015

Variable	Frequency	Percentage
Sex of child		
Male	**154**	**53.1**
Female	**136**	**46.9**
Age of child		
5-9 years	**99**	**34.1**
10-14 year	**191**	**65.9**
Education status of child		
Not Started	**23**	**7.9**
Kindargten	**42**	**14.5**
Primary(1-8)	**225**	**77.6**
Child lose any of Caregiver		
Yes	**119**	**41.0**
No	**171**	**59.0**
Who lose the child		
Father	**45**	**37.8**
Mother	**45**	**37.8**
Both mother and father	**29**	**24.4**

6.3 Clinical Related Characteristics of children

Among 290 children, they had a mean age at HIV diagnosis of enrollment were (4.4years ± 2.5, range1-12 years) and most of 64.6% CD4 count had >500 cell/ul, and about 224(77.2%) were normal nutritional status.All children were on ART (100%).More than half of 56.2% children were taking AZT, 3TC, NVP Drug regimen while only 22 children (7.4%) were also taking anti-tuberculosis medication. Almost, 77.9% wereWHOclinical stage one (Table 3).

Table 3: Clinical and health related Characteristics of Children in Dessie referral Hospital, 2015.

Variables	Frequency	percentage
Age at HIV diagnosis		
< 1 years	79	27.2
1-5 year's	115	**39.7**
>6 years	96	33.1
WHO clinical staging		
Stage I	226	**77.9**
StageII&III	64	22.1
ART Drug regimen taking		
AZT,3TC,NVP	163	**56.2**
AZT,3TC,EFV	82	28.3
others Regimen	45	15.5
Anti-Tuberculosis Drugs		
Yes	22	**7.7**
No	268	92.3
CD4count		
<350	52	17.9
350 -500	47	16.2
>500	191	**65.9**
Nutritional status		
underweight	66	22.8
Normal	224	**77.2**
OI prophylaxis		
Yes	245	**84.5**
No	45	15.5

6.4 Behavioral and Psychological characteristics of HIV infected children reported by caregivers

According to Caregiver- self reported adherence (69%) and (31%)were Adherent and Non-adherent respectively . Experienced stigma (7.2%) and (92.8%) were reported stigmatized and Non-stigmatized respectively and child depression symptoms (19.3%) and (80.7%) were reported depressed and Non-depressed respectively (Table 4).

Table 4: Behavioral and Psychological characteristics of HIV infected children reported by caregivers, Dessie referral hospital, 2015.

Variable	Frequency	Percent
Adherence status		
Adherent	200	**69.0**
Not Adherent	90	**31.0**
Stigmatized reported		
Not Stigmatized	269	**92.8**
stigmatized	21	**7.2**
Depression reported		
Not Depressed	234	**80.7**
Depressed	56	**19.3**

6.5Magnitude of HIV-Positive Status Disclosure to HIV infected children.

The prevalence of Disclosure of the children living with HIV **32.1 %(95% CI: 27%, 38%)** were disclosed HIV status to infected children by their caregivers/parents.

Themean age at disclosure was 10.1 years (±1.9years). More than half of children54.8%were disclosed by their Biological parents while 26.9 of children were disclosed by others (Healthcare provider, friends and neighbors) and Forty-eight (48.4%) of the disclosers were HIV-positive caregivers.

The prominent reasons for disclosure as mentioned by caregivers were “child refused medication (35.5%), repeated question asked “what happened to me” (27.9%), child thought to be matured” (22.6%) and Heard from friends and neighbors” (14%) (Figure 2).

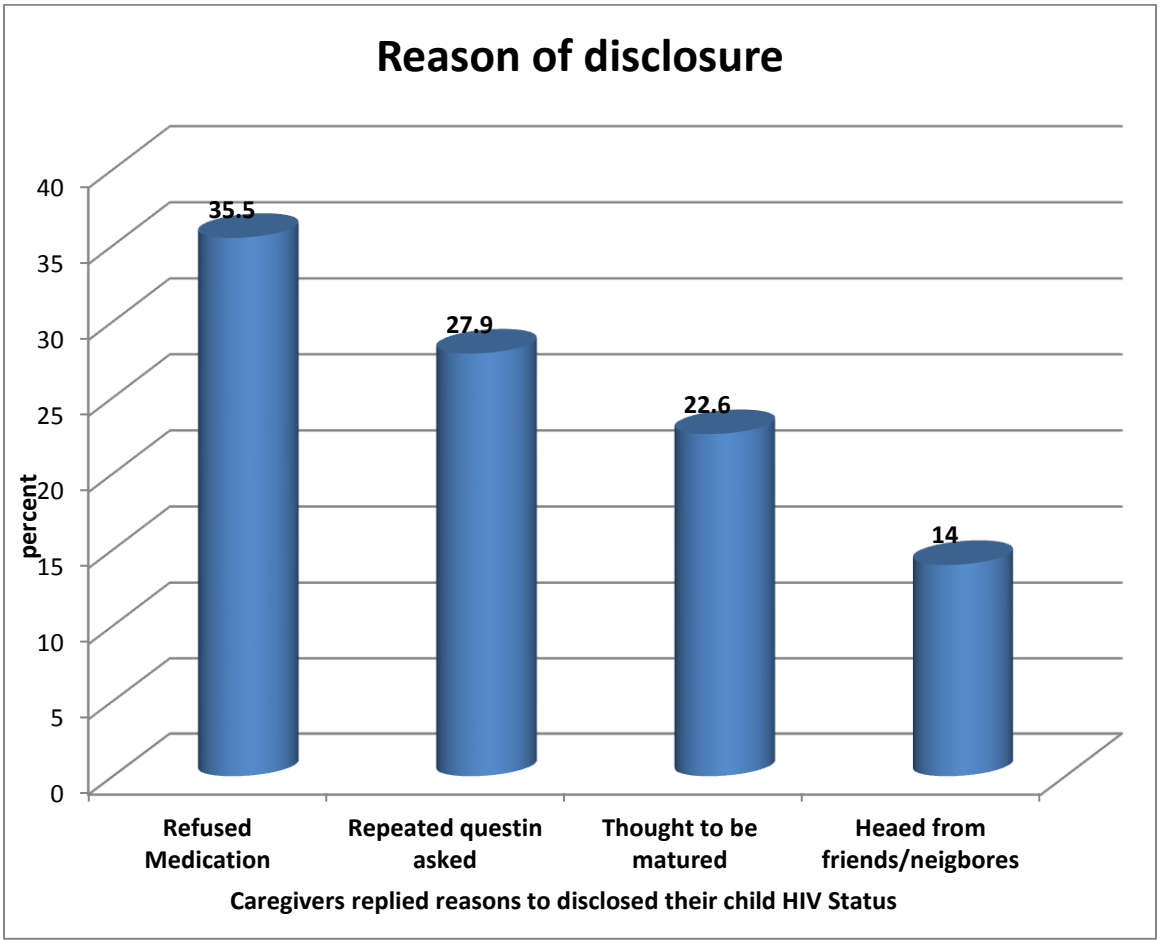

Figure 2: Reasons for Disclosing HIV Status to HIV infected Children by caregivers replied In Dessie Referral Hospital, 2015.

Caregivers/parents Replied that the reason for not disclosed HIV status to HIV Infected children

Parents/caregivers mentioned reasons for not disclosing to their child about his/her HIV positive status. More than one third (36%) still believedthat fear of self-discrimination; A quarter (25%) believed that the child is too young and another reasons about17.3 %,11.2% and 10.7%they believed that fear of negative emotional and health consequence, lack of Knowledge fordisclosure and child may not keep secret respectively (Figure 3).

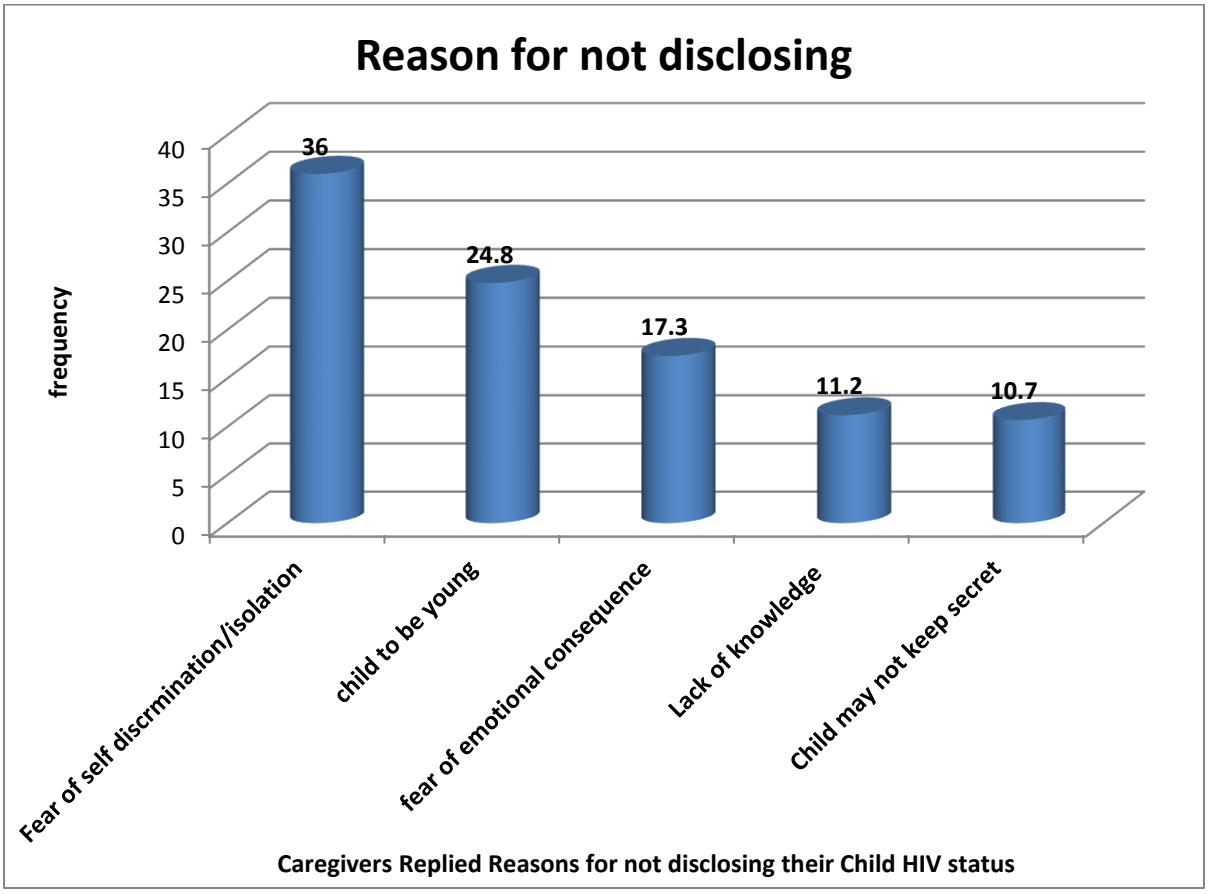

Figure 3: Reasons for not disclosingHIV Status to HIV infected Children by caregivers replied In Dessie Referral Hospital, 2015

Those caregivers did not disclose their child HIV status Beliefs, Future plan and preference to disclose HIV status to HIV infected children by caregivers, in Dessie Referral Hospital March 26 to May 13 2015.

Of the children who didn't know their HIV positive status, More than half 52.3%were reportedly child ever has asked why take medicine. About 177(89.8%) care givers replied they believed that advantage of disclosure to HIV infected children's. Almost 92% replied regarding future plan to be disclosed for their HIV infected children. Caregivers were also asked about the person who should be responsible for disclosure of HIV status to children and about 96 (48.7%) caregivers with the help of health care provider,41(20.8%) of them replied by caregiver and 60 (30.5%) by caregivers/parents (myself). Caregivers perceived that in what condition of disclosure happened More than three-fourth of care givers (85.%)mentioned that children have to be disclosed when feel healthy and only30 (15.2%) replied that disclosure to be done when at any health condition (when sick or healthy.)

6.6Factors Associated with HIV Positive Status Disclosure to HIV infected children

In the multivariate logistic regression age of the child, educationalstatus ofchild,caregivers relation to the child, CD4 count and Adherence reported were independently and significantly associated with disclosure of HIV-positive status to HIV infected children. However, factors related to the caregiver such as Age of care giver, marital status, HIV-positive status, and educational status, as well as Age at HIV diagnosis, ART regimen , and child lose any caregiver were not significantly associated with disclosure of HIV-positive status to HIV-infected children.

Accordingly, non-biological parents were 4.04 (AOR =4.04, 95% CI: 1.573, 10.374) times more likely to disclose HIV-status to HIV-infected children as compared to biological ones,CD4 count < 350 cell/um were 3.221(AOR=1.406 , 7.175) times more likely to disclose HIV status to HIV infected children as compare to > 500 CD4 count , Caregiver reported adherent were 6.939(AOR=6.939,95%CI:3.122 – 15.422) times more likely to disclosed HIV status to HIV infected children as compared to non-adherent children. Age of the child was one of the factors

significantly associated with disclosure ofHIVstatus in which children younger than10 years of age were 0.025(AOR = 0.025, 95% CI: 0.005, 0.119) times lesslikely to be disclosed as compared their counterparts.

Those children who not schooling were 0.182(AOR = 0.182, 95% CI: 0.42, 0.798) times less likely to be disclosed their HIV-p status as compared to attending Primary education (Table 4).

Table 5: Bivariate and multivariate analysis of factors associated with disclosure of HIV status to HIV-infected children in Dessie Referral Hospital, Northeast Ethiopia, 2015.

Variables	Disclosure status		COR(95%CI)	AOR(95%CI)
	Not Disclosed	Disclosed		
Age of caregiver				
<30 years	**64(32.5)**	25(20.9)	1	
30 - 50 years	**116(58.9)**	48(51.6)	1.059(.598- 1.876)	
> 50 years	**17(8.6)**	20(21.5)	3.012(1.36 -6.668)	
Marital Status				
Married	110(55.8)	41(44.1)	1	
Single	25(12.7)	17(18.3)	1.824(.894 ,3.722)	
Divorced	29(14.7)	10(10.8)	0.925(.414 ,2.07))	
Windowed	33(16.8)	25(26.9)	2.033(1.081, 3.822)	
Educational status of caregivers				
No formal Education	50(24.9)	25(20.9)	2.315(1.030 -5.203)	
Primary(1-8)	48(24.4)	31(33.3)	2.82(1.272-6.245)	
Secondary(9-120	52(26.4)	25(26.9)	2.1(0.933-4.718)	
College and above	48(24.4)	11(11.8)	1	
HIV status of Caregiver				
Positive	151(76.6)	58(62.4)	1	
Negative	46(23.4)	35(37.6)	1.981(1.162- 3.378)	
Age of children				
5-9years	87(44.2)	12(12.9)	**0.187(0.096 - 0.37)**	**0.025(.005-0.119)**
10-14 years	110(55.8)	81(87.1)	**1**	1

Educational child				
Not started	10(5.1)	13(14.0)	**0.24(0.08-0.714)**	**0.182(0.42- 0.8)**
Kindargten	32(16.2)	10(10.8)	**0.35(0.145, 0.83)**	**0.03(0.005 – 0.19)**
Primary(1-8)	155(78.7)	70(75.3)	**1**	**1**
Relationship for children				
Biological Parents	163(82.7)	60(64.5)	1	1
Grand parents	14(7.1)	19(20.4)	**3.687(1.74,7.814)**	**4.040(1.573 - 10.374)**
Relatives	20(0.2)	14(15.1)	**1.902(.903,4.003)**	**1.64(.659 - 4.105)**
Child Lose anycaregivers				
Yes	70(35.5)	49(52.7)	2.02(1.224-3.224)	
No	127(64.5)	44(47.3)	1	
CD4 count				
<350	25(12.7)	27(29.0)	**3.13(1.661-5.897)**	**3.22(1.41-7.18)**
350 -500	30(15.2)	17(18.3)	**1.642(.834 - 3.234)**	**2.36(1.019 -5.44)**
>500	142(72.1)	49(52.7)	1	
Age at HIV diagnosis				
<1years	68(34.5)	11(11.8)	1	
1-5 years	77(39.1)	38(40.9)	3.051(1.447,6.433)	
> 6 years	52(26.4)	44(47.3)	5.231(2.464 -11.11)	
Child ART drugregimen				
AZT,3TC,NVP	118(59.9)	45(48.4)	1	
AZT,3TC,EFV	46(23.4)	36(38.7)	2.052(1.178 - 3.58)	
Others regimen	33(16.8)	12(12.9)	0.954(0.453-2.01)	
Adherence reported				
Adherent	117(59.4)	83(89.2)	5**.68(2.776 -11.60)**	**6.939(3.122,15.242)**
Non-Adherent	80(40.3)	10(10.8)	1	1

7.Discussion

As children with HIV survive into adolescence and adulthood at unprecedented rates, disclosure of HIV status is an essential component of pediatric HIV care and long-term disease management. This study determined the prevalence and Associated factors of HIV status disclosure to HIV infected children's who had receiving HAART among caregivers of children aged 5 - 14 years in Dessie referral hospital pediatric ART clinics, Dessie , North East Ethiopia. This study found a minority of children aged 5–14 years**32.1 (95%CI: 27% - 38%)** knew HIV status, consistent with findings from studies in Thailand (30.1%)(19)and previous study in Bahirdar and Gondar ,Ethiopia (31.5%and 39.5%) and which found 231 and 428 children with a median age of 9.8(SD=2.6) and 9.96(SD=3)respectively (14, 15).but lower than the findings reported in California (USA) (43.1%)(28) The high level of disclosure in United States may be due to socio-cultural differences showing higher levels of expressiveness within the family and more intensive child-parent interactions which is not the case in most African countries, including Ethiopia.

The lower prevalence of disclosure in this study as compared to developed countries might be due to caregivers' thought child too young ,fear of stigma and discrimination and believed that their children would be isolated by their friends at school and in the community, and fear of negative consequences for the child. Caregivers were also lack knowledge and skills on how to approach/inform their HIV infected children about their HIV diagnosis in this study. On the other hand, in developed countries such as the USA, there are guidelines for disclosure of HIV positive status to children developed by the American Academy of Pediatrics(9),which contains detailed instructions on the process of disclosure but such guidelines do not exist in Ethiopia, although there was an effort of include issues related to disclosure in the new consolidated ''Guidelines for Pediatric HIV/AIDS Care in Ethiopia'' developed by the Federal HIV/AIDS Prevention and Control Office and Federal Ministry of Health in 2014(36).

However, the disclosure rate of children's HIV positive caregivers Asked about the person who should be the person responsible for disclosure of HIV status to children in this study, about 48% of them replied health caregivers with the help of healthcare

provider and 30% by caregiver or family. This result is little bit different with the study conducted in Addis Ababa, Ethiopia 60% believed that the doctor should be responsible(12), and in South Africa 55% who thought that the biological mother should be the one to disclose the HIV diagnosis to the child(37).

Age of child was found to be a significantly associated with disclosure of HIV positive status, children (6-9) years of age were 0.025 times less likely to be disclosed/informed of their HIV positive status as compared to their counterparts (AOR = 0.025 [95% CI = 0.005,0.119]). This result is consistent with the finding from others studies (14, 15, 37)and this showed that younger age of infected children as a determinant factor for HIV positive status disclosure. Likewise it is congruent with the study conducted in South Africa which showed the mean age at disclosure was 10.1 years (37) which was comparable with in the current study (9.8 years). The educational status of child was found to be significant associated factors ofHIV status disclosure, children not started education were 0.182 times less likely to be disclosed HIV status as compared primary education.The study is consistent in sub-seharan Africa and North Indian(38-40). It might be related to younger age of childrenand not attending school was lesslikely to hear regarding theHIV status than their counter parts.

In this study, when children currently live with non-biological caregivers were more likely to disclose the child's HIV-positive status than biological caregivers. This finding is in agreement with studies done in Ethiopia, Philadelphia and Thailand (14, 18, 41) where most children who knew their diagnosis were living with caregivers who were not their biological parents , whereas the majority of children who did not know the diagnosis were living with biological parents. As argued by these studies biological parents might not be willing to confront the fact of their own responsibilities in passing the infection onto their children.

In this study< 350 CD4 cell/mm3 more likely associated to disclose HIV status as compare to >500 CD4cell/mm3 ,it is consistent to a study Thai found that while disclosure was associated with CD4 below 30%(42).

In contrast, a study in Romania found that children who did not know their HIV status were at higher risk for disease progression, measured by CD4 count decline and death compared to disclosed children.(28)

It is found thatstrong association with care givers reported who had adherent childrenwere more likely to disclosed HIVstatus than caregiver self-reported non - adherent. Disclosure is a traumatic event for many children and can be accompanied by feelings of anger, hopelessness and rebellion, which may lead to temporary or longer-term adherence problems. Adherence issues may be compounded by other specific factors such as increased incidence of depression(43)and generally poorer medication adherence among this age group(43, 44). On the other hand, there are also reasons to believe disclosure may lead to improved adherence, including increased responsibility over medication-taking and better access to social support. Pediatric HIV providers often recommend disclosure of HIV status to children as necessary to building trusting provider-patient and family relationships and developing disease management skills that facilitate adherence.(44) In USA only longitudinal study to assess adherence pre- and post-disclosure, reported that approximately 58% of children and their caregivers reported that adherence improved post-disclosure(24).

8. Limitation

Self-reports information on adherence, and experiences of stigma and depression May not be enough to be used.

The cross-sectional design of this study did not allow us to measure causal pathways of disclosure or the potential impact of disclosure on Adherence and CD4 count.

9 .Conclusions

The magnitude of disclosure of HIV positive status to HIV infected children was found to be low and Children younger than 10 years of age, Children Educational status, Non-biological caregivers, and caregivers reported adherent and <350CD4cell/mm3 were significantly associated with disclosure of HIV positive status to HIV infected children .

10 Recommendation

Health care provider

Improving and focusing counseling services for caregivers through professionally skilled counselors are important for timely disclosures.

It is important to improve child adherence to disclose their HIV status timely.

Health professional should be discussing the HIV status of children at their appointment date and should give focus for non- schooling children to disclose at appropriate time.

Caregivers of children

Biological parents have to disclose to their HIV status to HIV infected children at appropriate time.

They should be encourage children to ask question, do not be disappointed if they do not react in the manner you expected.

MOH/RHB

Existing materials on disclosure should be made available for adaptation, evaluation and broader implementation.

Researcher

Prospective study on disclosure of HIV status in this setting are needed to answer these important questions as more HIV-infected children and adolescents make the difficult transition to adulthood.

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12: Annexes

Annex I: English Information Sheet

Introduction

This information sheet is prepared to explain the research project that you are asked to join by a group of research investigators. The main aim of the study is to assess Disclosure of HIV status to HIV infected children and associated factors in Dessie Referral Hospital.

The research team includes a final year MPH graduate student, one health officer; three ART trained nurses from Dessie Referral Hospital.

Name of Principal Investigator: ShimelsNegash
Name of Advisors: Mr. Kefyalew Addis and Mr. DigsuNegesse
Name of the Sponsor:
Name of Organization: University of Gondar, Institute Public Health College of Medicine and Health Science

This information sheet is prepared by above mentioned researcher whom main aim is to assess Disclosure of HIV status to HIV infected children and associated factors in Dessie referral Hospital North East, Amhara Region Ethiopia, and 2015.

The investigator is a final year MPH student with his advisors from Institute of public health, college of medicine and health sciences, university of Gondar.

Purpose: The purpose of this research study is toassess Disclosure of HIV status to HIV infected children and associated factors in Dessie referral Hospital. North East, Amhara Region, Ethiopia, Results from this study will be used to assist in decision making and planning for improving, preparing of health care providerto be given attention ongoing counseling and advocating the importance of disclosure of HIV status to infected children.

Procedure: This study uses institution based quantitative cross-sectional study design, through using interview with standard structured Questionnaire and Permission will be processed from the University of Gondar and medical director of Dessie referral hospital.

Risk and/or Discomfort: There is no any risk or discomfort that you will face by participating in this research except dedication of time for responding the questions.

Any personal will be kept confidentially. There is no any risk in participating in this research project.

Benefits: There will be benefit for Dessie Referral Hospital, Dessietown woreda administration, Zonal health desk, Amhara regional health Bureau and stake holders who work in Pediatrics and HIV and as well for the participants. The findings of the study are no doubt to implement the intervention.

Incentives/Payment for Participating: There is no incentive or payment to be gained by taking part in this project.

Confidentiality: All Personal identification& personal information will not be taken that is anonymous. The information collected from this research project will be kept confidential. Information will be accessed by the researcher and research assistant only.

Persons to contact: This research project will be reviewed and approved by the ethical committee of the University of Gondar. If you want to know more information you can contact the committee through the address below. If you have any question you may contact the following individuals.

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Annex II:የአማርኛየመረጀዉልቅጽ

የምርምርፕሮጀክቱርዕስ -

በደሴሆስፒታልወላጆቻቸዉወይምአሳዳጊዎቻቸዉየኤች.አይ.ቪ.ቫይረስላለባቸዉህጻናትስለማሳወቅከማሳወቅምጋርተያያ ዥነትያለቸዉንጉዳዮቸማጥናት

የዋናተመራማሪዉስም- ሽመልስነጋሽ

የድርጅቱስም፡በጐንደርዩኒቨርሲቲህክምናናጤናሳይንስኮሌጅየህብረተሰብጤናአጠባበቅኢንስቲትዩት

ወጭዉንየሚሸፍነዉአካል፡-

መግቢያ፡-

ይህመረጃናስምምነትየተዘጋጀበትዋናአላማበምርምርፕሮጀክቱየሚሳተፉየምርምርፕሮጀክቱአባላትስለፕሮጀክቱእንድያብ ራሩበትታስቦነዉ፡፡የጥናቱቡድንምሥስትድግሪያላቸዉንነርሶች፣አንድድግሪያለዉንተቆጣጣሪናሁለትአማካሪዎችንከጐንደር ዩኒቨርሲቲያከተተነዉ፡፡

ጥናቱየሚካሄድበትምክንያት፡-

የፕሮጀክቱዋናአላማምንያህሉቫይረሱበደማቸዉየሚገኝህጻናትስለራሳቸዉበወላጆቻቸዉወይምበተንከባካቢዎቻቸዉእንደ ተነገራቸዉ ና ስለበሽታዉከመንገሩሂደትጋርተያያዥነትያላቸዉንጉዳዮችማጥናትናማወቅሲሆንበተጫማሪምበጥናትላይየተመሠረተየጤና ፖሊሲለማዉጣትእንደምያግዘየታመነበትነዉ፡

አተገባበር: በደሴሆስፒታልየሚገኙየኤች.አይ.ቪቫይረስበደማቸውውስጥያለየኤች.አይ.ቪህክምናአገልግሎትተጠቃሚ ህጻናትንስለረራሳቸዉጤንነትሁኔታማሳወቅበተዘጋጀዉጥናትድርሻእንድኖሪዎጋብዘነዎታል፡፡በፕሮጀክቱለመሳተፍፈቀዴኛ ከሆኑሊፈርሙይገባል፡፡ከዚያምበመረጃሰብሳቢዎችምላሽዎንእንድሰጡይጠየቃሉ፡፡በዚህጥናትእንድሳተፉየተመረጡትበና ሙናአወሳሰድስልትነዉ፡፡የሚሰጡትመረጀበአጠቃለይናየጥናቱዉጤትበተናጠልማንምበማያገኛዉመልኩበመለያቁጥርሚ ስጢራዊነቱየተጠበቀይሆናል፡፡

ሊገጥምየምችልችግርወይምአለመመቸት፡-

በዚህጥናትበመሳተፍዎምንምአይነትየሚደርስብዎችግርየለም፡፡መጠይቁንለመሙላትየተወሰነሰአት(15-20ደቂቃ) ሊወስድበዎይችላልነገርግንይህጥናትለወደፊቱለልጅዎለዕርስዎናለህብረተሰቡካለውጥቅምአኳያይህብዙአይደለም፡፡ስለዚህ የእርስዎመልስከፍተቱንለማሳየትናለማሻሻልጠቃሚግብዓትነዉ፡፡

ጥቅሞች፡-

በዚህምርምርስላተሳተፉለእርስዎበቀጥታወይምበተዘዋዋሪጥቅምይኖረዎታል፡፡ምክንያቱምጥናቱየኤች.አይ.ቪቫይረስበደማ ቸውውስጥያለየኤች.አይ.ቪህክምናአገልግሎትተጠቃሚ ህጻናትስለበሽታቸዉማሳወቅሂደትናጠቀሜታለማሻሻልያለመበመሆኑእርስዎናቤተሰብዎየአገልግሎቱተጠቃሚይሆናሉና፡፡

ለመሳተፍጥቅማጥቅም/ክፍያ: በዚህጥናትበመሳተፍዎምንምክፍያአይሰጥዎትም፡፡

ሚስጢራዊነት፡ከዚህምርምርፕሮጀክትየተሰበሰበመረጀምስጢራዊይሆናል፣ስለእርስዎየተሰበሰቡትመረጃዎችስምዎሳይጸፍ በትበሚስጥርይያዛልይህምከዋናተመራመሪዉበስተቀርማንምእዳያዉቀዉያደርጋል፡፡

ዕንቢየማለትወይምየማቋረጥመብት፡በዚህምርምርየመሳተፍምሆነያለመሳተፍሙሉመብትአለዎት፡፡ጥያቄዎቹንሙሉምሆነበ ከፊልመልስአለመስጠትይችላሉ፡፡ይህደግሞማንኛዉንምየጤናአገልግሎትከማገኛትአያግድወትም፡፡እንድሁምበማንኛዉም በፈለጉሰዓትያለምንምመቀጮየማቋረጥሙሉመብትአለዎት::ሊያገኙአቸዉየሚችሉአቸዉሰዎች:-

ይህየምርምርፕሮጀክትበጐንደርዩኒቨርሲቲየጥናትናምርምርስነምግባርኮሚቴተከልሶይጸድቃል::ተጨማሪመረጀማወቅከፈ ለጉየኮሚቴዉንአባላትከዚህበታችባላዉአድራሻማግኘትይችላሉ፡፡ጥያቄከለዎትከሚከተሉትግለሰቦችማናቸዉንምበፈለጉሰ ዓትመጠየቅይችላሉ፡፡

- አቶሽመልስነጋሽ ፡
- አቶከፍያለዉአዲስ፡በጐንደርዩኒቨርሲቲህክምናናጤናሳይንስኮሌጅየህብረተሰብጤናአጠባበቅትምህርትቤትስልክ+2519 20256699 ኢ ሜል፡kefadis@gmail.com
- አቶድግሱነገሰ ፡ በጐንደርዩኒቨርሲቲህክምናናጤናሳይንስኮሌጅየህብረተሰብጤናአጠባበቅትምህርትቤትስልክ +251920256699 ኢ ሜል፡digsuneg@gmail.com

AnnexIII: English Consent Form (Certificate)

A questionnaire prepared by university of Gondar Medical and Health Sciences Institute of Public Health On Assessment Of Disclosure HIV Status To HIV Infected Children And Associated Factors in Dessie Referral Hospital ART Clinic.

Introduction:

My name is ……., I am working in Dessie Hospital, I am interviewing Caregivers/parents who has child on ART Follow up in this hospital. The purpose of this questionnaire is to gather information to find out the rate of Disclosure practice among parents/caregivers and associated factors with HIV status disclosure to your child .after the study is completed the result will be given for responsible bodies to act accordingly and improve the service. I will ask you some questions which will take 15-25 minutes. The answer to those questions is confidential. I will not write your name in the questionnaire. You can refuse and interrupt to respond to any of the questions. There is no harm or cost to participate in the study.So I kindly request your cooperation and time for this short interview session. if you are willing to participate ,please give your written or finger print consent for the one who will interview you .

Thank you

Would you participate in responding to the questions in this questionnaire? Yes___No_____

NameandSignature/finger print of the participants_____

Name and Signature of the data collector _____

Name of Investigator: ShimelsNegash

Address of the investigator: 0911558363, Gondar, Ethiopia

Questionnaire No_____

Interviewee Code_____

Date of Interview_____

Annex IV: English Version Questionnaire

Instructions:

Fill in the blank space.

Circle the appropriate answer.

Do not omit any item of information

1,Question related to Socio-Demographic characteristics of parent's/caregivers			
NO	Question	Response category	Code
101	Place of residence	1,Urban 2,Rural	
102	Sex of care givers	1,Male 2,Female	
103	How old are you?	_____.(in years)	
105	Religion	1,Orthodox 2.Muslim 3,Catholic 4,Protestant 5, Others (Specify)……	
106	Which education level do you accomplish?	1,Can't read and write 2,Read and write only 3,Primary school(1-8) 4,Secondary school(9-12) 5,College and above	
107	What is your occupation?	1,Housewives 2,Government employee 3,Farmer 4,Merchant 5,Daily laborer 6,Others(specify)	
108	What is your Marital status?	1,Married 2,Single 3,Divorced/ 4,Windowed 5,Separate	
109	What is your monthly in come?	_____in Birr.	

2,Socio-Demographic characteristics of the child			
201	Sex	1,Male 2,Female	
202	Age	_____(in years)	
203	Which educational levels do your child attended?	1,Not started Education 2,Kindargten 3,Primary(1-8) 4,Secondary(9-12)	
3. Questions for the care giver/parent			
301	Have you ever been tested for HIV?	1,Yes 2,No	If2>Q305
302	Would you like tell me your (the caregivers) HIV status?	1,Yes 2,NO	If 2 >Q305
303	IF Yes, What is your HIV status?	1,Positive 2,Negative	
304	If positive, are you on HAART?	1,Yes 2,No	
305	Does the child lose any of his/her parents due to HIV?	1,Yes 2,No	IF2 > Q307
306	If yes, lost who? (Multiple response is possible)	1,Mother 2,Father 3,Both mother and father 4,Other family member/sibling	
307	What is your relationship with the children?	1, Biological Parents 2,Grand Parents 3,Orphanage	
308	Does the child know that's/he comes to the clinic for HIV care?	1,Yes 2,No	
309	Does the child know that the name of his/her illness?	1,Yes 2,No	
310	Does the child know that s/he is taking medicine for HIV?	1,Yes 2,No	
311	Does the child know that s/he has HIV?	1,Yes 2,No	IF2 the → Q316

312	If yes at least one Q308 -3011 Who has disclosed that information?	1,Biological parents 2,Grand Parents 3,Otherfamily Members 4,Health care providers 5,Others (Specify)_____	
313	What is the HIV status the one who Disclosed?	1,Positive 2,Negative 3,Don't Known 4, Do notwilling to tell	
314	How old was when s/he is told her/his HIV status?	_____ in years	
315	What was the reason for disclosure?	1,The child thought to be matured 2,Child refused to take medication/to go clinic on appointment date 3,S/he heard the diagnosis from friends /Neighbors 4,Repeated question by the child what happened to him/her 5,othersreason(Specify)_____	
316	(IF No Q No 307) IF not disclosed about the disclosure status what is the reason for not disclosing the child HIV status to their child itself?	1,Child is too young 2,Fear of Negative emotional and Health consequence 3,Because of S/he can not kept secret 4,The child can not understand 5,Don not know the advantage of telling(Disclosing) 6,Fear of Child Discrimination 7,Others(Specify)_____	
317	Dose the child ever ask question about why s/ has taken medicine?	1,Yes 2,No	
318	Do you think that Disclosing the HIV diagnosis	1,Yes	

	to an infected child has advantage?	2,No 3,I don't Know	
319	Do you have an intention to Disclosed the HIV Diagnosis to the child in the future?	1,Yes 2,No	
320	IF Yes Q No 320 How would you want to disclose HIV diagnosis to the child?	1,To disclose by myself 2,To disclose by a health care providers 3,To disclose by myself, but with the help of care providers	
321	When do you think a child should be disclosed for his/her HIV status ?	1,At any time 2,When Sick 3,When Relatively health	
4,Questionarie related Adherence stigma and Depression items			
401	Dose the child ever refuse to take medicine s/he is supposed to take?	1,Yes 2,No	
402	Do you ever not give the medicine because you do not want to give them in front of another people?	1,Yes 2,No	
403	Do you ever have problems with giving the medicine because the child does not know why s/he is taking them?	1,Yes 2,No	
404	Does the child ever have problems taking the medicine on time or taking them every day?	1,Yes 2,No	
405	Do other children avoid plying with the child because of her/his HIV status?	1,Yes 2,No	
406	Do other children tease or call the child names because of her/his HIV status?	1,Yes 2,No	
407	Has your child been rejected by friends or family because of her/his HIV status?	1,Yes 2,No	
408	Does your child seem to have little interest or pleasure in doing things lately?	1,Yes 2,No	

409	Has your child been feeling down, depressed or hopeless?	1,Yes 2,No	
5. secondary data Clinical markers of HIV infected children from ART record			
501	Age at diagnosis of HIV	_____in years	
502	What is the current WHO clinical Stage?	1,T-Staging I 2,T-Staging II 3,T-StagingIII 4,T-Staging IV	
503	What is the child current CD4 count?	_____	
504	What is the child taking ARTregimen?	_____	
505	What is the child weight current?	_____(Kg)	
506	Dose the child has currently on Anti TB?	1,Yes 2,No	
507	Dose the child has currently taking Co-trimoxzol?	1,Yes 2,No	

Thank you for your responses!

Annex V: አማርኛየፈቃደኝትመጠይቂያቅጽ

በጎንደርዩኒቨርሲቲ፣በህክምናእናጤናሳይንስኮሌጅየህብረተሰብጤናአጠባበቅኢንስቲትዩትሰለኤችአይቪሁኔታለራሳቸዉቪ
ይረሱበደማቸዉላለባቸዉልጆችበወላጆቻቸዉ/በተንከባካቢዎቻቸዉመንገርወይምማሳወቅናከማሳወቅጋርተያያዥነትያላቸ
ዉንጉዳዮችአስመልክቶየተዘጋጀመጠይቅ

<u>መግቢያ፤</u>

ጤናይጥልኝ፣ሰሜ_____ይባላል፣ደሴሆስፒታልዉስጥነዉየ
ምሰራዉ፡አሁንበዚህሆስፒታልውስትየህክምናከትትልለሚያረጉልጆችላላቸዉአሳዳጊዎችናዎላጆችመጠይቄንአቀርባለሁ፡፡
ከዚህበመቀጠልለማካሄድስላሰብኩትጥናትገለጻአደረግልዎታለሁ፡ይህጥናትየሚያተኩረዉበደማቸዉየኤችአይቪቫየረስላለ
ባቸዉልጆችሰለማሳወቅሲሆንአላማዉሀ/ምንያህሉቫይረሱበደማቸዉየሚገኝልጆችሰለራሳቸዉበሽታበቤተሰቦቻቸዉወይም
በተንከባካቢዎቻቸዉእንደተነገራቸዉለማወቅ፤ለ/
ሰለበሽታዉከመንገሩሂደትጋርተያያዥነትጉዳዮችማጥናትናማወቅነዉ፡፡እርስዎምየዚህጥናትአካልይሆኑዘነድበትህትናእጠይ
ቅዎታለዉጥናቱምሲጠናቀቅየተገኘዉንዉጥትለሚመለከታቸዉአካላትበማቅረብለህጻናትየሚደረገዉንእንክብካቤለማሻሻ
ልጥረትአደርጋለሁ፡፡እንዲረዱትየምፈልገዉነገር፡ሀ/ከእርስዎየሚሰበሰበዉንመረጃሚስጥሮችሙሉበሙሉየሚጠበቅመሆኑ
ንለ/የቃለመጠይቅወረቀቱላይስምዎትየማይሰፍርመሆኑን፤የምንጠቀመዉመለያቁጥርብቻመሆኑንሐ/በጥናቱመሳተፍዎምን
ምአይነትጉዳትእንደማስከትልብዎመ/በመጨረሻምበጥናቱያለመካፈልመበትዎየተጠበቀመሆኑንይሆናልጊዜዎንለማካፈል
ዝግጁበመሆንዎበቅድሚያአመሰግናለሁ

ስለዚህፈቃደኛከሆኑምስክርነትዎንበቃልእንዲሰጡኝእጠይቃለሁ

›–_____ ¾KU_____

¾}dò¬eU“ò`T/¾×ƒ ›h^_____

¾S[Í cwdu=¨<eU“ò`T_____

የጥናቱባለቤትስምናፊርማ : አቶሽመልስነጋሽ_____

አድራሻስልክ/ሞባይል -251911558363 ኢ.ሜል-shimels_1@yahoo.com

SÖÃl ¾}VLuƒ k” _____

¾S[Í Scwcu=Á pêlØ`_____

የተሳታፊዉኮድ_____

Annex VI: አማርኛመጠይቅ

ትዛዝ፡ ባዶቦታዉንይሙሉ፤ትክክለኛዉንመልስያክብቡ፤ምንምአይነትመረጃአትለፉ

ክፍልአንድአጠቃላይጥያቄየቤተሰብ /ተንከባካቢበተመለከተየሚሞላ			
ተ.ቁ	ጥያቄ	አማራጭመልስ	ኮድ
101	መኖሪያአድራሻ	1,ከተማ 2,ገጠር	
102	ጾታ	1ወንድ 2 ሴት	
103	እድሜ	_____(ዓመት)	
104	ሃይማኖት	1,ኦርቶዶክስ 2,ሙስሊም 3,ካቶሊክ 4,ፕሮቴስታንት 5, ልላ/ይገለጽ_____	
105	የትምርትደረጃ	1,ማንበብናመጻፍ እማይችል 2,ማንበብናመጻፍ የሚችል 3,,ያንደኛ ደረጃ(1-8) 4,ሁለተኛ ደረጃ(9-12) 5,ኮልጅናከዚያ በላይ	
106	የስራሁኔታ	1,የቤት እመቤት 2,የመንግስት ሰራተኛ 3,ገበሬ 4,ነጋዴ 5,የቀን/የጉልበትሰራተኛ 6,ሌላ/ይገለጽ_____	
107	የጋብቻሁኔታ	1,,,ያላገባ/ች 2,,ያገባ/ች 3,አግብቶ የፈታ/ች 4,የሞተባት/የሞተችበት 5,ሌላ/ይገለጽ_____	
108	የገቢሁኔታወርሃዊገቢበብር?	_____ ብር	
ክፍልሁለት፡ የህጻኑን/ኗንሁኔታበተመለከተየሚሞላ			
201	ጾታ	1,ወንድ 2,ሴት	
202	እድሜ	_____(አመት)	
203	የትምህርትደረጃ	1,,ያልጀመረ/ች 2,,መዋለህጻናት 3,,የመጀመሪያ ደረጃ(1-8)	

		4, ሁለትኛደረጃ(9-12)	
ክፍልሦስት :የወላጅ/የተንከባካቢየጤናጋርየተገናኘጥያቄ			
301	የኤችአይ ቪ ምርመራአርገዉያዉቃሉ?	1,አዎ 2,አይ የለም	መልሶ 2 ከሆነበቀጥታ ጥ.ቁ 305 ይለፉ
302	እባክዎንሰለእርስዎኤችኤይ ቪ ሁንታሊነግርዎንይችላሉ ?	1,አዎ 2,አልችልም	መልሶ 2 ከሆነበቀጥታ ጥ.ቁ 305 ይለፉ
303	እሺካሉየምርመራዎትንሁንታቢነገሩን?	1,ኤች አይ ቪ ፖዘቲቭ 2,ኤች አይ ቪ ነጌቲቭ	
304	ፖዘቲቭከሆኑጸረኤችአይ ቪ መድሀኒትይወሰዳሉ?	1,አዎን 2,አልወስድም	
305	ልጁ/ቷ በኤችአይቪምክንያትያጣዉ/ችዉቤተሰብአለ ?	1,አዎ 2,አላጣም/ችም	መልሶ 2 ከሆነበቀጥታ ጥ.ቁ 307 ይለፉ
306	አዎካሉማንኛቸዉን ?	1,እናት 2,አባት 3,እናትናአባት 4,ሌላ ቤተሰብካለ	
307	ልጁ/ቷ አሁንከማንጋርነዉየሚኖረዉ/የምትኖረዉ?	1,ከእናትናከአባት ጋር 2,ከዘመድ ጋር 3,ማሳደጊያ ድረጅትዉስጥ	
308	ልጁ/ጅቷለኤችአይ ቪ ህክምናከትትልወደከሊኒእንደመጣያዉቃል?	1,አዎ 2,አይ አታቅም/ያቅም	
309	ልጁ/ቷ ያለባቸዉኤችአይ ቪ /በሽታስምያወቃል/ታዉቃለች?	1,አዎ 2,አይ አያዉቅም /አታዉቅመ	
310	ልጁ/ቷ የጸረኤችአይመድሃኒትየሚወስዱመሆናቸዉንያዉቃሉ?	1,አዎ 2,አያዉቅም /አታዉቅም	
311	ለጁ/ጅቷኤችአይ ቪ እንዳለባቸዉያወቃሉወይ?	1,አዎ 2,አይ አታዉቅም/አያዉቅም	ከጥያቄ 308 -311 ለሁሉምመልሶች 2 ከሆነበቀጥታጥ.ቁ 316 ይለፉ
312	ከላይካሉትጥያቄ 308 – 3011 አንዱአዎከሆነለልጅ/ቷ ኤችአይ ቪ አንዳለባቸዉየተነገራቸዉ/ያሳወቃቸዉማነዉ?	1,ወላጆች 2,አያቶች 3,ሌላ የቤተሰብአባል 4,የጤና ባለሙያ 5,ሌላ ካለይገለጽ	
313	ለልጁ/ቷ ሰለኤችአይ ቪ የተናገዉሰዉየኤችአይ ቪ ሁንታዉምንድንነዉ?	1,ኤች አይ ቪ ፖዘቲቭ 2,ኤች አይ ቪ ኔጌቲቭ	

		3,አላወቅም 4,ለመናገር ፈቃደኛአይደለሁም	
314	ስለበሽታዉ/ኤችአይ ቪ ሲነገረዉ/ራትእድሜዉ/ዋ ስንትነበር?	_____ አመት	
315	ለልጁ/ቷ ስለበሽታዉለመንገርምክንያትምንነበር?	ነ,ልጁ/ቷ እድሜዉብቁመሆኑንበማሰብ 2,ለጁ/ቷ ህክምናዉንለመከታተል /ክሊኒክበቀጠሮሰአትለሜሄድስላልሆነ/ች 3,ከጓደኞቹ/ቿ /ከጎረቤትስለሰማ/ች 4,ምን እንደሆነ/እንዳጋጠመዉበተደጋጋሚጥያቄበማንሳ ቱ/ቷ 5,ሌላ ምክንያት	
316	ለልጁ/ቷ ስለበሽታዉ /ዋ ካለተነገረዉ/ራትምክንያቱ?	ነ,ለጁ/ቷ አድሜዉ/ዋ ስላልደረሰ 2,ሰሜታዊና የተሳሳተአመለካከተሰለጤናያለዉንለዉጦችበመ ፍራት 3,ሚስጢር ሰለማይጠበቅ/ትጠብቅ 4,ቢነገረዉ/ራትሰለማይገነዘቡ 5,መናገር ወይምመግለጽጥቅምእንዳለዉባለማወቅ 6,ልላ ምክንያትካለይገለጽ	
317	ልጁ/ቷ ስለበሽታቸዉ /ኤችአይ ቪ /ሁኔታእማያወቁከሆኑለምንወደክሊኒክወይምመ ድሃኒቱንለምንእነደሚወስድምንምክንያትይሰጣሉ ?	_____	
318	ልጁ/ቷ ለምንመድሃኒትእንደሚወስዱጥያቄጠይቀዉኢያ ዉቁምወይ?	ነ,አዎ 2,አያዉቅም/አታወቅም	
319	አንድልጅለኤችአይ ቪ መጋለጡንመሳወቅ /መንገርጥቅምያለዉይመሰሃል/ሻል?	ነ,አዎ 2,አይመስለኝም 3,አላወቅም	
320	ወደፊትልጁለኤችአይ ቪ መጋለጡንለማሳወቅ/ለመናገርአላማአለህ/ሽ?	ነ,አዎ 2,አይ የለኝም	
321	መልስዎአዎከሆነየበሽታዉንሁኔታለህጻኑ/ኗ በማንቢነገረዉ/ራትትመርጣለህ /ትመርጫለሽ?	ነ,በራሴ /በእኔ 2,በጤና ባለሙያዎች 3,በእኔናበጤናባለሙያዎች	
322	ባንተ/ቺ አመለካከትልጆችመቼነዉየጤንነትሁኔታቸዉንወ ይምለኤችአይ ቪ መጋለጣቸዉንማወቅያለባቸዉ ?	ነ,በማነኛዉም ግዜናወቅት 2,ሲያማቸዉ 3,ጤንነት ሲሰማቸዉ	

ክፍልአራት፡መጠይቅየመድሃኒትቁርኝትመገለልንናየአይምሮድብርትንየተመለከተለወላጆች/ለአሳዳጊዎች		
401	ልጁ/ቷ ጸረኤችአይ ቪ አልወስድምብለዉአያዉኩመወይ?	1,አዎ 2,አይ አያዉቅም/አታዉቅም
402	መድሃኒቱንለልጁ/ጅቷሳይሰጡትየቀረጊዜየለምሰዉስላለላለመሰጠትፈልገዉ?	1,አዎ 2,አይ የለም
403	ችግርአጋጥምዎትአያወቅምየጸረኤችአይ ቪ መድሃኒትአልወሰድምብለዉምክንያቱመልጁ/ቷ ኤችአይ ቪ እንዳለበት/ባትስለመያዉቅ/ታዉቅ?	1,አዎ 2,አይ የለም
404	ችገርአጋጥመዎትአያወቅመለጁ/ቷ በሰአቱወይምበየቀኑጸረኤች ኤ ቪ መድሃንቱንበሚሰጡዋቸዉገዜ?	1,አዎ 2,አይ የለም
405	ሌሎችልጆችከልጅዎጋርአንጫወትምብለዉያዉቃሉምክንያቱምልጅኤችአይ ቪ ስላለባቸዉ?	1,አዎ 2,አይ የለም
406	ሌሎችልጆችልጅዎትላይይቀልድባቸዋልወይምበኤችአይቪዉምክንያትበመጥፎይጠሩታል/ዋታል?	1,አዎ 2,አይየለም
407	ለጁ/ቷ በኤችአይ ቪ ምክንያትበጓደኞቹ/ቿ ወይምበቤተሰብችላይባላሉ?	1,አዎ 2,አይ የለም
408	እንደዉለጁን/ጅቷንስመለከተዋቸዉነገሮቸንበሚሰሩጊዜፍለጎቱ/ቷ ወይምደሰታዉ/ዋ የቀነሰ/ች ይመስልዎታል?	1,አዎ 2,አይ የለም
409	ልጁ/ጅቷየመደበትየመፈዘዝእናተስፋየመቁረጥስምትነበረዉ/ራት?	1,አዎ 2,አይ የለም
5. secondary data Clinical markers of HIV infected children from ART record		
501	Age at diagnosis of HIV	_____in
502	What is the current WHO clinical Stage?	1,T-Staging I 2,T-Staging II 3,T-Staging III 4,T-Staging IV
503	What is the child current CD4 count?	_____
504	What is the child Taking ART regimen?	_____
505	What is the child weight at baseline?	_____
506	Dose the child has currently on Anti TB?	1,Yes 2,No
507	Dose the child has currently taking Co-trimoxzol?	1,Yes 2,No

ለሰጡንምላሽበጣምእናመሰግናለን

Annexes VII: Declaration

I, the undersigned, Master of Public health declare that this thesis is my original work in partial fulfillment of the requirement for the degree of Master of Public Health.

Name: Shimels Negash

Signature: _____

Place of submission: Institute of public Health, College of Medicine and Health Sciences, University of Gondar.

Date of Submission: _____

This thesis work has been submitted for examination with my/ our approval as university advisor(s).

Advisors

Name Signature

_____

_____ _____